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Original Article

The relationship between social support and health-related quality of life in patients with antiphospholipid (Hughes) syndrome

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Abstract

Objective. Antiphospholipid (Hughes) syndrome (APS) is recognised as a systemic autoimmune disease defined by recurrent thromboembolic events and/or pregnancy morbidity. Little is known about the psychological burden of this long-term condition. This study aims to explore the relationship between social support and health-related quality of life (HRQoL) in patients with APS.

Methods. 270 patients with a clinical diagnosis of APS participated in a cross-sectional online questionnaire survey. Data included: demographics, disease-related information, social support and HRQoL.

Results. Both perceived and ideal social support were associated with HRQoL in APS. Patients reported receiving insufficient social support. Perceived emotional support was related to physical functioning (B=7.77, p=0.006, 95% CI: 2.25, 13.29); perceived instrumental support was associated with bodily pain (B=17.52, p<0.001, 95% CI: 11.15, 23.90) and perceived informational support with physical and social functioning (B=-6.30, p=0.05, 95% CI: -12.52, -0.08; B=8.06, p=0.02, 95% CI: 1.17, 14.94). Ideal emotional support was related to physical and social functioning (B=5.80, p=0.04, 95% CI: 0.26, 11.34; B=7.53, p=0.04, 95% CI: 0.55, 14.51); ideal instrumental support was associated with mental health (B=4.73, p=0.03, 95% CI: 0.38, 9.07) and ideal informational support with vitality (B=5.85, p=0.01, 95% CI: 1.23, 10.46).

Conclusion. Social support was linked to HRQoL in patients with APS. Insufficient social support was associated with limitations in various HRQoL domains. Increasing social support especially through provision of disease-specific education might contribute to improving HRQoL in patients with APS. Patient-tailored interventions addressing psychosocial aspects of living with APS are needed to improve patients' psychological and physical status.

Key words: Antiphospholipid (Hughes) syndrome (APS); social support; health-related quality of life (HRQoL); short-form health survey (SF-36)

Introduction

Antiphospholipid (Hughes) syndrome (APS) is recognized as a chronic autoimmune disease and is characterized by recurrent venous and arterial thrombosis, miscarriage, neurological features such as stroke, headache, fatigue, memory loss, and epilepsy [1, 2].

Approximately 20% of strokes in people under 40 years and up to 25% of all spontaneous miscarriages (two or more) or fetal losses are due to APS [2, 3]. APS affects predominantly women of childbearing age and is categorized as primary (PAPS) if there is no associated connective tissue disease and secondary (SAPS) if there is, mainly systemic lupus erythematosus (SLE), but also rheumatoid arthritis (RA), Sjogren's syndrome (SS), scleroderma, vasculitis, and Crohn's disease [4, 5, 6].

Chronic conditions such RA, SLE, ankylosing spondylitis (AS) and fibromyalgia syndrome (FS) have been shown to have a negative impact on health-related quality of life (HRQoL) especially if there is significant amount of pain involved [4, 5, 7, 8]. Similarly, in APS, HRQoL has been reported to be poorer compared to the general population [9, 10] especially in patients who had a history of arterial thrombosis [10].

The role of the social environment in patients' HRQoL is very important [11]. The term social support denotes the availability and provision of care and help from an individual's environment. There are several kinds of social support. Three types of social support often discussed in the literature are distinguished into tangible support such as instrumental support (e.g. assistance with medication/housework), informational support (e.g. education regarding the illness) and treatment strategies and recovery and into intangible support in the form of emotional support (e.g. listening/sympathy) [12]. Social support can be problematic despite people's good intentions [13] when it involves excessive worry and unsolicited advice, denial of the existence of the illness and its impact on the patient's life, or support that is not consistent with patients' beliefs about their condition [13].

Social support is important in improving and maintaining both good physical and mental health in order to self-manage a chronic illness effectively [14, 15]. Support from others, computer-based support and educational interventions combined with self-management [16, 17] and internet support groups [18] have all shown beneficial effects. Elements included in support are also disease-related education such as

diagnosis, treatment, and recovery. Increased levels of disease-specific knowledge were associated with stronger coping skills, perceptions and health behaviours, benefiting disease progression as well as psychological well-being [19, 20]. Social support can also play a mediating role through influencing self-esteem by increasing optimism and decreasing depression thus improving psychological adjustment to chronic illness [21]. Indeed, patients who received more emotional support on a daily basis reported better psychological status than those who did not [22].

Two levels of social support are described: perceived and ideal support. Perceived support refers to the support people perceive to be receiving from their environment while ideal support is the support they would still like to be receiving from friends and family based on their individual needs. It has been argued that the first is more important than the latter because the way patients interpret social support influences psychological adjustment and coping more than ideal support [23, 24]. In addition, lack of understanding from their environment regarding their illness and its consequences contributes to poorer adjustment to chronic illness [23]. In the present study we explored both forms of social support because we attempted to evaluate the magnitude of discrepancy of perceived and ideal social support in patients with APS and whether this discrepancy was associated with their HRQoL. Furthermore, we wanted to assess how much social support patients with APS feel they still need compared to how much they feel they are receiving in order to be able to provide them with additional support to improve their HRQoL.

Availability of social support is related to improved health in patients with rheumatic diseases [25, 26]. Particularly, in SLE clinical variables appear to exert a minor influence on patients' HRQoL [5, 27] with psychosocial factors such as social support or helplessness having a significant impact [5, 28]. In addition, "invalidation" referring to lack of understanding or acknowledgment and rejection of the condition has been associated with poorer outcome in patients with rheumatic diseases such as FS and RA [29]. Findings from a literature review on the role of social support in SLE, indicated that social support contributes as a predictor of disease activity, damage and quality of life on both the physical and emotional level [30].

While social support has a beneficial impact on both HRQoL and adjustment to their illness in patients with rheumatic diseases, little is known about the role of social support in HRQoL in patients with APS.

This highlights the need for the present study which aimed to explore the relationship between perceived and ideal social support and HRQoL in APS.

Methods

Participant selection and assessment

This was an internet-based cross-sectional survey. The survey was conducted through a link to an online questionnaire which was available at *KwikSurveys.com.* The link was included in an email that was sent to all members of the Hughes Syndrome Foundation (HSF) worldwide with a request to participate in the survey – if they fulfilled the eligibility criteria. The email was sent by the HSF manager to preserve confidentiality. Participants were given three weeks to complete the survey online after receipt of the email containing the link. As soon as a survey questionnaire was completed, a link leading to each participant's responses was automatically forwarded to the researchers' personal email inbox that was set up for the purpose of the study. The link expired 6 months after completion of the survey.

The survey consisted of three sections: (a) the SF-36 assessing health-related quality of life; (b) social support questions; and (c) demographic and disease-specific data. A reminder to complete the survey was sent four days before the expiry of the deadline. The HSF manager forwarded the link to 443 members worldwide to ensure anonymity of the participants. Inclusion criteria were that participants had to be over 18 years of age and have a clinical diagnosis of either PAPS or SAPS. The study received approval from the University of Nottingham Research Ethics Committee.

HRQoL measure

The SF-36 was employed in the current study due to its generic scope, as well as its reliability and validity in assessing HRQoL in healthy populations [31] and in other diseases [32] despite not having been used in APS before. The SF-36 can also provide data on the influence of the disease on patients' physical psychological and social well-being [33, 34].

Specifically, the SF-36 measures eight domains relative to physical and psychological status which are termed "physical components" (PC) and "mental components" (MC). The physical components include: role physical (RP), general health (GH), bodily pain (BP), and physical functioning (PF) while the mental components encompass: role emotional (RE), vitality (VT), mental health (MH), and social functioning (SF). The self-administered standard version of the SF-36 was selected since it was based on self-completion. Multipoint scales (3 to 10 items) are used to score six of the eight domains while SF and BP are scored on a two-point scale (yes/no). Scale scores are computed by same scale item summation followed by transformation of raw scale score on a range from 0 (lowest possible level of functioning) to 100 (highest possible level of functioning) [36].

Demographics and disease-specific information

Demographics included questions on participants' age, gender and ethnic background. Information on type and time of diagnosis, co-morbidities, date of symptom onset, and number of medications prescribed was collected.

Social support survey

Social support was assessed on two levels, perceived and ideal, and on three subscales, emotional, instrumental and informational. The survey questions were presented in the form of a set of multiple choice questions with 4 or 5 possible options *displaying various examples of social support scored on a two-point scale.* The participants had to indicate which of the available support options listed (e.g. *for* ***emotional support****: (a) listening; (b) understanding; (c) encouragement; (d) positive feedback; (e) willingness to learn more about the illness)* they felt they were receiving (perceived support) and which one(s) they would like to still be receiving (ideal support) by simply ticking the appropriate answer yes or no (please see Appendix 1).

Statistical Analysis

Participant characteristics summary measures and HRQoL scores were computed as means and standard deviations for continuous (approximate) normally distributed variables and frequencies and percentages for categorical variables. Normality of distribution of continuous summary scales (all *p*-values >0.05) was assessed with the Shapiro-Wilk test. Multiple linear regression analysis was performed to explore associations between social support and HRQoL in patients in APS and to examine whether perceived and ideal social support were associated with HRQoL. All analyses were adjusted for age. All *p*-values were two-sided throughout and significance level was set at 5% level. The data were analysed using SPSS version 21.

Results

Participant characteristics

The majority of participants were from the United Kingdom (61.9%). Approximately a quarter were from the United States (24.8%), and fewer from Australia (2.2%), Canada (1.9%) and several other countries. Response rate was 60%. 274 patients completed and returned the questionnaire survey out of a total of 443 individuals who were sent the questionnaire survey link. Four questionnaires were discarded due to insufficient data which resulted in 270 completed questionnaires being included in the analyses. Mean patient age was 45.2±12.1 (range: 18-86 years). The majority of the patients were female (84%; n=226) and 45% reported PAPS. Mean age for patients with PAPS was 42.6±11.6 years and for patients with SAPS 47.4±12.1 years. The mean time until receiving a clinical diagnosis for APS was 48.5±87.3 months for PAPS and 75.8±106.4 months for SAPS patients. PAPS patients were prescribed a mean of 3±2.8 medications while SAPS patients 7±5.2. SLE was reported by 43% (n=63) of SAPS participants. On average, participants completed the survey five years post-diagnosis.

Social support

Frequency statistics were computed separately for actual and idea social support measures. The majority of patients indicated that they were perceived to be receiving emotional support such as listening (78.7%), understanding (59%), encouragement (55.6%) but not positive feedback (34% vs 66%) and willingness on behalf of their family and friends to learn more about APS (44% vs 56%). In contrast, the majority of patients perceived not to be receiving instrumental support such as help with childcare and housework/shopping (85.1% and 51.9% respectively), provision of transportation (69.8%), financial help (73.5%) and someone to accompany them to GP and hospital appointments (51.5%). Most of the information support, APS patients perceived to be receiving was derived from the internet (82.1%) and support groups (65.7%) whereas a minority of patients reported perceived informational support obtained from GPs (26.9%) and TV or leaflets (14.2%) (Table 1).

The main social support (ideal) that patients would like to receive were: understanding (67.9%), willingness to learn more about APS from family or friends (64.9%), information from GPs (74.3%), TV and leaflets (50%) (Table 1).

HRQoL

HRQoL scores were computed for all patients. Mean scores in six domains (RP, BP, GH, VT, SF and RE) were <60 which is the cut-off score reported to indicate highest specificity for functional limitations [51]. In the remaining two SF-36 domains (PF and MH), mean scores were >60. The mean HRQoL score was 64.4±20.6. Comparison between PAPS and SAPS patients showed poorer HRQoL scores for the PAPS group (< 60) in two domains (GH and VT) and better HRQoL scores (>60) in the remaining six domains (PF, RP, BP, RE, MH and SF) with a mean of 65.15±31.1. For SAPS patients, mean scores were <60 in seven of the SF-36 domains (RP, BP, GH, RE, VT, MH and SF) and >60 in one domain (PF) with a mean of 60.25±23.1.

Relationship between social support and HRQoL in APS

Perceived social support and HRQoL

Perceived social support was assessed on three levels: emotional, instrumental and informational. On the perceived emotional level, results showed that higher levels of encouragement were related to better physical functioning (B=7.77, p<0.01; 95%CI: 2.25, 13.29), better role physical functioning (B=15.83; p<0.01; 95%CI: 3.96, 27.70) and better general health (B=5.62; p<0.01; 95%CI: 1.02, 10.22) while less understanding from friends and family were associated with lower levels of vitality (B=-6.22, p<0.01; 95%CI:-10.91, -1.53). Lower provision of positive feedback was associated with poorer role emotional functioning (B=-13.88, p<0.05; 95%CI: -26.51, -1.25) and poorer mental health (B=-7.99, p<0.001; 95%CI: -12.52, -3.47) and similarly lower degree of willingness to learn more about APS was also related to poorer mental health (B=-4.27, p<0.05; 95%CI: -8.51, -0.02) (Table 2).

Results on perceived instrumental support indicated that lower provision of help with childcare was related to more limited social functioning (B=-9.21, p<0.05; 95%CI: -18.49, 0.07) whereas more support in terms of helping with housework and/or shopping were associated with better physical functioning (B=13.50, p<0.001; 95%CI: 8.17, 18.84), role physical (B=18.64, p<0.01; 95%CI: 6.88, 30.40), lower bodily pain (B=17.52, p<0.001; 95%CI: 11.15, 23.90), better general health (B=10.40, p<0.001; 95%CI: 5.94, 14.87), higher levels of vitality (B=8.85, p<0.001; 95%CI: 4.30, 13.39), and better social functioning (B=9.22, p<0.01; 95%CI: 2.71, 15.73). Provision of transportation was associated with better HRQoL in all domains except for mental health while financial help was associated with better physical functioning (B=7.93, p<0.01; 95%CI: 1.70, 14.16) and lower bodily pain (B=9.31, p<0.05; 95%CI: 1.77, 16.85). Attendance at General Practitioner (GP) and hospital appointments was also related to better HRQoL in the domains physical functioning (B=9.20, p<0.001; 95%CI: 3.71, 14.69), bodily pain (B=9.74, p<0.01; 95%CI: 3.09, 16.39), general health (B=5.53, p<0.05; 95%CI: 0.92, 10.14), and role emotional (B=12.14, p<0.05; 95%CI: 0.12, 24.15) (see Table 3).

Perceived informational support was associated with HRQoL in terms of information provided by GPs, support groups, and consultants/charity. Less information provided by GPs was associated with more limited physical functioning (B=-6.30, p<0.05; 95%CI: -12.52, -0.08), and poorer role physical performance (B=-19.37, p<0.01; 95%CI: -32.63, -6.11), more support provided by support groups was related to better social functioning (B=8.06, p<0.05; 95%CI: 1.17, 14.94) and less information from

consultants/charity was related to poorer general health (B=-8.67, p<0.05; 95%CI: -16.72, -0.61) (Table 4).

Ideal social support and HRQoL

Ideal social support was also assessed on three levels: emotional, instrumental and informational. Patients reported the levels of social support they felt they still wanted to receive based on their needs. People who felt they still needed someone to listen to their concerns and worries would be more likely to have better physical functioning if they had this support (B=5.80, p<0.05; 95%CI: 0.26, 11.34) and higher levels of vitality (B=6.91, p<0.01; 95%CI: 2.32, 4.51). The need for understanding was linked to better HRQoL except for bodily pain and role emotional and the need for more frequent encouragement was associated with better physical functioning (B=7.78, p<0.01; 95%CI: 2.30, 13.26), role physical (B=14.46, p<0.05; 95%CI: 2.66, 26.26), and greater vitality (B=5.16, p<0.05; 95%CI: 0.56, 9.77). Greater provision of positive feedback was associated with better role physical (B=16.35, p<0.01; 95%CI: 4.59, 28.12), greater vitality (B=5.29, p<0.05; 95%CI: 0.69, 9.90), and role emotional (B=13.13, p<0.05; 95%CI: 1.23, 25.04). Patients' greater need for their family and friends to learn more about APS was related to better role physical (B=15.99, p<0.01; 95%CI: 3.62, 28.36), and greater vitality (B=7.21, p<0.01; 95%CI: 2.42, 12.01) (Table 5).

Ideal instrumental support was associated with better HRQoL in all domains in terms of provision of help with housework and/or shopping and attendance at GP and hospital appointments (see Table 6). The need for provision of transportation was related to better HRQoL in all domains except role physical and role emotional (see Table 6).

There was an association between greater informational support provided by and better role emotional (B=19.05, p<0.01; 95%CI: 5.39, 32.70) and better mental health (B=6.29, p<0.01; 95%CI: 1.35, 11.23), while information from support groups was associated with greater vitality (B=5.85, p<0.01; 95%CI: 1.23, 10.46) (Table 7).

Discrepancy values between perceived and ideal social support

In order to examine discrepancy between actual and ideal social support in APS patients, the total values of each were computed for all three types of social support, i.e. emotional, instrumental and informational. Following that, a discrepancy value was obtained by subtracting the total actual support values from the total ideal support values for each of the three types of social support. The results indicated that the mean of the discrepancy value between actual and ideal emotional support (*M*=.064; *SD*=2.42; N=268) as well as the mean of the discrepancy between actual and ideal instrumental support (*M*=-.011; *SD*=1.24; N=268) were relatively small. In contrast, the mean of the discrepancy between ideal and actual informational support (*M*=.23; *SD*=1.58; N=268) was large. Thus, it would seem that the informational support APS patients perceive to be receiving is far smaller than the support they ideally would need to be receiving. As far as informational and instrumental support was concerned, the ideal levels of social support did not appear to differ significantly from the perceived levels.

Discussion

This is the first study to examine associations between social support and HRQoL in patients with APS. HRQoL in individuals living with rheumatic and autoimmune diseases is affected to a significant extent [4, 5] with social support playing a significant role [18, 37-39]. However, very little research has been conducted into HRQoL and social support in patients with APS so far, to our knowledge. A variety of measures are available to assess HRQoL including generic and disease-specific instruments. Generic instruments can be employed across a range of different conditions while specific instruments are disease-adapted. APS-related symptoms vary significantly and can have an impact on patients' physical, social and emotional status [1].

Associations between perceived social support and HRQoL indicated that higher provision of instrumental support was related to better HRQoL in terms of patients' physical and mental status. Higher perceived emotional support, on the other hand, led to better mental health status probably because increased support in this domain may contribute to patients getting more time to rest, socialize and experience less stress [43-46]. More perceived information provided by GPs was also related to better

physical functioning and role physical, while information received from support groups was related to better social functioning and less information from consultants and the charity were related to poorer general health. This is in accordance with previous literature which suggests that doctor-patient communication plays a significant role in patients' health outcomes, quality of life, absence from work and treatment adherence [47]. It could be assumed that because of insufficient information provided, patients are not aware of the degree they should engage in various activities and this subsequently may have a negative effect on their physical health due to increased or decreased involvement.

Similarly, higher ideal social support was also linked to better HRQoL. People who felt they needed someone to listen to their concerns and worries were predicted to be more likely to have better physical functioning such as fewer limitations in performing physical activities, including bathing or dressing and experience greater vitality i.e. feeling more energetic. This could be attributed to the fact that people might be likely to receive some reassurance from their social circle that they are able to perform certain activities following the expression of their concerns or offer them additional support which might contribute to decrease the burden that affect their energy levels. This was also reflect in the fact that the need for more frequent encouragement was associated with better physical while greater provision of positive feedback was associated with better role physical greater vitality, and role emotional.

The need to feel understood by family and friends was linked to better HRQoL in all domains except for physical pain and role emotional. Indeed, negative social responses, particularly discounting (rejecting) and lack of understanding (not being acknowledged), were associated with poorer health among patients with fibromyalgia and rheumatoid arthritis [52]. Greater understanding would be derived from better knowledge of APS by the patient's family and social circle. Results showed that patients' greater need for their family and friends to learn more about APS was related to better role physical, and greater vitality. Ideal instrumental support was associated with better HRQoL in all domains in terms of provision of help with housework and/or shopping and attendance at GP and hospital appointments and greater informational support was associated with better role emotional and better mental health, while information from support groups was associated with greater vitality.

In order to assess whether the social support that patients reported to be receiving was significantly different to the support they felt they still needed, results did not show a statistically significant difference

for emotional and instrumental support. However, there was a statistically significant difference between the informational support patients reported to be receiving and the informational support they felt they were still lacking highlighting the lack of awareness as well as health professional education and public awareness about APS. More knowledge of APS provided by health care professionals and the media might enhance patients' coping with the disease due to increased education on aspects such as self-management, and medication and more effective and helpful support from their families and friends.

There are some limitations to this study. First, the participants were members of the HSF which might have increased the likelihood of receiving higher social support compared to patients who do not belong to a charity. The data was based on self-report thus environmental or emotional influences could not be controlled. Diagnosis of APS could not be confirmed due to lack of access to patients' medical records or physical and laboratory examination. The survey was cross-sectional which prevents detection of change over time and assessment of causal relationships. Findings cannot be generalized due to the fact that the majority of patients were female and British. Ethnicity and culture has been suggested to affect perceived quality of life of individuals on dialysis after renal transplant with Asian renal patients perceiving HRQoL more negatively than white Europeans [47]. Factors such as major life events, for example death, divorce or severity of disease and depression status were not controlled for, any of which could potentially be related to poorer HRQoL in either group. Many factors such as bereavement, financial difficulties, depression and anxiety were also found to place a burden on HRQoL [11].

Strengths of this study, on the other hand, include a high response rate (60%), a satisfactory sample size providing sufficient power for analyses. The fact that a relatively non-researched patient population was assessed was a further advantage. Examination of all aspects of patients' well-being relating to the psychological, social and physical impact of APS and its influence by social support measures provided a more holistic approach and increased understanding of the degree and nature of the disease impact on patients' HRQoL.

Findings indicated that certain types of social support exert a significant influence on a variety of domains in APS patients' HRQoL. Patients reported receiving insufficient social support. By extension, this might be suggestive of the beneficial effect of social support on HRQoL in patients with APS either through medication adherence or also through more effective coping skills. Lack of support in terms of providing

disease – and medication-specific information has been associated with decreased medication adherence in patients with autoimmune diseases [48]. In addition, increased informational support especially by knowledgeable health professionals might improve provision of support by patients' family and friends through reducing "invalidation" [29]. Particularly, due to the multi-faceted nature of APS, as is true of most autoimmune diseases, involving pain, disability, uncertainty about its progression and fear of treatment effects and based on the current findings it can be suggested that a combination of approaches and interventions could prove to be of great importance and help in improving adjustment and coping with APS. This combination would need to incorporate social approach and support from practitioners, family, friends, and co-workers, as well as elements from both the bio-psychosocial and biomedical frameworks [49, 50] tailored to the needs of APS patients. Specific strategies could be implemented through both primary and secondary care and include patient- and family/friends-education sessions delivered by specialist nurses. These sessions could provide disease- and treatment-specific information and self-management strategies such as International Normalised Ratio (INR) measuring, dietary advice and pacing to patients as well as disease-related information and ways of supporting their loved one in coping more effectively with APS to families/friends of patients with APS.

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Conflict of interest

None

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Table 1 Computed values of results for ideal and actual social support

Actual Social Support - Emotional (n=268)	Yes	No
Listening	211 (78.7%)	57 (21.3%)
Understanding	158 (59%)	110 (41%)
Encouragement	149 (55.6%)	119 (44.4%)
Positive Feedback	91 (34%)	177 (66%)
Willingness to learn more about APS	118 (44%)	150 (56%)
Actual Social Support - Instrumental (n=268)		
Help with childcare	40 (14.9)	228 (85.1%)
Help with housework/ shopping	129 (48.1%)	139 (51.9%)
Provision of transportation	81 (30.2%)	187 (69.8%)
Financial help	71 (26.5%)	197 (73.5%)
Attendance GPs/hospital appt	131 (48.9%)	137 (51.5%)
Actual Social Support - Informational (n=268)		
Information provided by GPs	72 (26.9%)	196 (73.1%)
Information provided on the internet	220 (82.1%)	48 (17.9%)
Information provided by support groups	176 (65.7%)	92 (34.3%)
Information provided on TV/ leaflets	38 (14.2%)	229 (85.4%)
Information provided by consultants/charity (n=20)	19 (7.1%)	1 (0.4%)

Ideal Social Support - Emotional (n=268)	Yes	No
Listening	136 (50.7%)	132 (49.3%)
Understanding	182 (67.9%)	86 (32.1%)
Encouragement	127 (47.4%)	141 (52.6%)
Positive Feedback	125 (46.6%)	143 (53.4%)
Willingness to learn more about APS	174 (64.9%)	94 (35.1%)
Ideal Social Support - Instrumental (n=268)		
Help with childcare	41 (15.3%)	227 (84.7%)
Help with housework/ shopping	121 (45.1%)	147 (54.9%)
Provision of transportation	66 (24.6%)	202 (75.4%)
Financial help	68 (25.4%)	200 (74.6%)
Attendance GPs/hospital appt	109 (40.7%)	159 (59.3%)
Ideal Social Support - Informational (n=268)		
Information provided by GPs	199 (74.3%)	69 (25.7%)
Information provided on the internet	119 (44.4%)	149 (55.6%)
Information provided by support groups	119 (44.4%)	149 (55.6%)
Information provided on TV/ leaflets	134 (50.0%)	134 (50.0%)
Information provided by consultants/charity (n=42)	41 (15.2%)	1 (0.4%)

Table 2 Associations between perceived emotional support and HRQoL in APS

	Perceived Social Support – Emotional (n= 270)				
SF-36 domains	***Listening***	***Understanding***	***Encouragement***	***Positive Feedback***	***Willingness to learn more about APS***
PC	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)
Physical functioning	-0.50 (-7.29, 6.30)	-2.62 (-8.31, 3.06)	7.77** (2.25, 13.29)	0.43 (-5.47, 6.33)	4.21 (-1.21, 9.62)
Role physical	5.90 (-8.68, 20.48)	-5.60 (-17.79, 6.60)	15.83** (3.96, 27.70)	4.84 (-7.82, 17.50)	0.32 (-11.37, 12.01)
Bodily pain	2.97 (-5.25, 11.19)	-2.23 (-9.08, 4.62)	6.62 (-0.08, 13.33)	0.43 (-6.68, 7.53)	1.35 (-5.21, 7.91)
General health	-2.74 (-8.40, 2.92)	-1.74 (-6.46, 2.98)	5.62** (1.02, 10.22)	-0.45 (-5.35, 4.46)	0.57 (-3.96, 5.10)
MC					
Vitality	-3.66 (-9.35, 2.03)	-6.22** (-10.91, -1.53)	1.74 (-2.94, 6.41)	-4.23 (-9.13, 0.68)	-3.62 (-8.15, 0.92)
Social functioning	-3.82 (-11.88, 4.25)	-4.60 (-11.30, 2.11)	1.82 (-4.80, 8.43)	-3.64 (-10.61, 3.33)	-3.03 (-9.47, 3.41)
Role emotional	-9.60 (-24.24, 5.03)	-7.56 (-19.83, 4.71)	-2.45 (-14.55, 9.65)	-13.88* (-26.51, -1.25)	-10.38 (-22.06, 1.31)
Mental health	-3.44 (-8.78, 1.90)	-3.99 (-8.43, 0.44)	-2.57 (-6.95, 1.81)	-7.99*** (-12.52, -3.47)	-4.27* (-8.51, -0.02)

Multiple Linear Analysis examining the association between perceived emotional support and HRQoL variables adjusted for age; SF-36: Medical Outcomes Study Short-Form 36; PC: physical component; MC: mental component; CI: confidence intervals **p<0.05; **p<0.01; ***<0.001*

Table 3 Associations between perceived instrumental support and HRQoL in APS

	Perceived Social Support – Instrumental (n= 270)				
SF-36 domains	***Help with childcare***	***Help with housework/ shopping***	***Provision of transportation***	***Financial help***	***Attendance at GPs/ hospital appointments***
PC	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)
Physical functioning	0.24 (-7.63, 8.10)	13.50*** (8.17, 18.84)	15.03*** (9.26, 20.81)	7.93** (1.70, 14.16)	9.20*** (3.71, 14.69)
Role physical	1.09 (-15.83, 17.99)	18.64** (6.88, 30.40)	20.20** (7.40, 32.99)	11.21 (-2.28, 26.69)	8.92 (-3.06, 20.91)
Bodily pain	0.15 (-9.50, 9.81)	17.52*** (11.15, 23.90)	14.59*** (7.51, 21.67)	9.31* (1.77, 16.85)	9.74** (3.09, 16.39)
General health	0.75 (-5.82, 7.31)	10.40*** (5.94, 14.87)	6.03* (1.03, 11.03)	3.88 (-1.36, 9.12)	5.53* (0.92, 10.14)
MC					
Vitality	-0.08 (-6.69, 6.52)	8.85*** (4.30, 13.39)	8.48*** (3.50, 13.46)	1.67 (-3.62, 6.95)	1.18 (-3.50, 5.87)
Social functioning	-9.21* (-18.49, 0.07)	9.22** (2.71, 15.73)	10.43** (3.34, 17.52)	2.10 (-5.39, 9.58)	5.26 (-1.34, 11.86)
Role emotional	-8.29 (-25.25, 8.67)	5.59 (-6.45, 17.62)	14.95* (1.97, 27.92)	7.15 (-6.44, 20.74)	12.14* (0.12, 24.15)
Mental health	-3.26 (-9.44, 2.93)	2.46 (-1.91, 6.83)	3.63 (-1.12, 8.38)	0.33 (-4.63, 5.30)	-0.22 (-4.62, 4.18)

Multiple Linear Analysis examining the association between perceived instrumental support and HRQoL variables adjusted for age; SF-36: Medical Outcomes Study Short-Form 36; PC: physical component; MC: mental component; CI: confidence intervals **p<0.05; **p<0.01; ***<0.001*

Table 4 Associations between perceived informational support and HRQoL in APS

	Perceived Social Support – Informational (n= 270)				
SF-36 domains	***Information provided by GPs***	***Information provided on the internet***	***Information provided by support groups***	***Information provided on TV/leaflets***	***Information provided by consultants/charity***
PC	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)
Physical functioning	-6.30* (-12.52, -0.08)	-2.17 (-9.50, 5.16)	4.20 (-1.65, 10.05)	4.42 (-3.49, 12.33)	-3.02 (-12.74, 6.69)
Role physical	-19.37** (-32.63, -6.11)	-3.52 (-19.16, 12.11)	6.93 (-5.65, 19.51)	8.03 (-8.99, 25.05)	-14.63 (-35.45, 6.20)
Bodily pain	-6.12 (-13.63, 1.39)	3.02 (-5.65, 11.69)	4.57 (-2.50, 11.64)	6.15 (-3.37, 15.66)	-5.52 (-17.19, 6.15)
General health	-0.50 (-5.71, 4.70)	0.41 (-5.61, 6.43)	2.07 (-2.80, 6.95)	2.89 (-3.66, 9.44)	-8.67* (-16.72, -0.61)
MC					
Vitality	-4.59 (-9.80, 0.62)	1.50 (-4.56, 7.56)	0.65 (-4.26, 5.56)	-2.40 (-8.99, 4.19)	-1.18 (-9.35, 6.99)
Social functioning	-6.79 (-14.16, 0.58)	-2.63 (-11.20, 5.94)	8.06* (1.17, 14.94)	8.86 (-0.42, 18.14)	-9.34 (-20.85, 2.18)
Role emotional	-11.02 (-24.49, 2.40)	-13.45 (-29.21, 2.31)	5.10 (-7.57, 17.76)	-2.99 (-20.12, 14.13)	-8.62 (-29.59, 12.36)
Mental health	-1.12 (-6.03, 3.80)	-4.08 (-9.74, 1.59)	-1.09 (-5.69, 3.52)	-1.71 (-7.90, 4.48)	-3.72 (-11.38, 3.94)

Multiple Linear Analysis examining the association between perceived informational support and HRQoL variables adjusted for age; SF-36: Medical Outcomes Study Short-Form 36; PC: physical component; MC: mental component; CI: confidence intervals**p<0.05; **p<0.01; ***<0.001*

Table 5 Associations between ideal emotional support and HRQoL in APS

	Ideal Social Support – Emotional (n= 270)				
SF-36 domains	***Listening***	***Understanding***	***Encouragement***	***Positive Feedback***	***Willingness to learn more about APS***
PC	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)
Physical functioning	5.80* (0.26, 11.34)	6.21* (0.31, 12.10)	7.78** (2.30, 13.26)	3.99 (-1.54, 9.54)	4.91 (-0.89, 10.71)
Role physical	5.76 (-6.21, 17.73)	14.27* (1.61, 26.93)	14.46* (2.66, 26.26)	16.35** (4.59, 28.12)	15.99** (3.62, 28.36)
Bodily pain	0.23 (-6.50, 6.96)	5.87 (-1.26, 12.99)	2.66 (-4.04, 9.35)	-0.005 (-6.70, 6.69)	0.75 (-6.27, 7.76)
General health	2.06 (-2.57, 6.70)	5.66* (0.77, 10.56)	3.64 (-0.96, 8.24)	1.41 (-3.21, 6.02)	2.30 (-2.53, 7.14)
MC					
Vitality	6.91** (2.32, 4.51)	9.48*** (4.64, 14.32)	5.16* (0.56, 9.77)	5.29* (0.69, 9.90)	7.21** (2.42, 12.01)
Social functioning	5.55 (-1.03, 12.12)	7.53* (0.55, 14.51)	6.31 (-0.23, 12.85)	4.10 (-2.47, 10.66)	4.77 (-2.10, 11.65)
Role emotional	9.91 (-2.10, 21.92)	4.88 (-7.95, 17.72)	7.69 (-4.29, 19.67)	13.13* (1.23, 25.04)	8.41 (-4.15, 20.96)
Mental health	2.32 (-2.06, 6.69)	6.17** (1.57, 10.78)	2.55 (-1.81, 6.90)	1.68 (-2.68, 6.04)	1.74 (-2.83, 6.30)

Multiple Linear Analysis examining the association between ideal emotional support and HRQoL variables adjusted for age; SF-36: Medical Outcomes Study Short-Form 36; PC: physical component; MC: mental component; CI: confidence intervals **p<0.05; **p<0.01; ***<0.001*

Table 6 Associations between ideal instrumental support and HRQoL in APS

	Ideal Social Support – Instrumental (n= 270)				
SF-36 domains	***Help with childcare***	***Help with housework/ shopping***	***Provision of transportation***	***Financial help***	***Attendance at GPs/ hospital appointments***
PC	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)
Physical functioning	-0.64 (-8.56, 7.28)	10.77*** (5.33, 16.20)	11.28*** (4.99, 17.58)	3.67 (-2.72, 10.07)	11.81*** (6.29, 17.33)
Role physical	-1.50 (-18.54, 15.54)	20.03*** (8.29, 31.77)	12.93 (-0.83, 26.69)	11.59 (-2.05, 25.24)	18.78** (6.77, 30.79)
Bodily pain	-4.52 (-14.13, 5.09)	12.01*** (5.45, 18.58)	10.63** (2.95, 18.31)	4.50 (-3.16, 12.17)	9.87** (3.12, 16.62)
General health	0.75 (-5.82, 7.31)	8.48*** (3.95, 13.00)	5.58* (0.25, 10.91)	2.41 (-2.91, 7.73)	7.36** (2.71, 12.01)
MC					
Vitality	3.91 (-2.68, 10.50)	11.69*** (7.24, 16.14)	9.35*** (4.07, 14.64)	5.17 (-0.15, 10.49)	9.86*** (5.25, 14.47)
Social functioning	0.83 (-8.52, 10.18)	11.82*** (5.37, 18.28)	11.88*** (4.37, 19.40)	1.64 (-5.94, 9.22)	9.94** (3.31, 16.58)
Role emotional	0.97 (-16.15, 18.08)	16.75** (4.85, 28.66)	12.12 (-1.72, 25.96)	10.53 (-3.26, 24.32)	14.28* (2.07, 26.48)
Mental health	0.83 (-5.37, 7.03)	4.73* (0.38, 9.07)	5.79* (0.77, 10.82)	3.56 (-1.45, 8.57)	4.46* (0.02, 8.90)

Multiple Linear Analysis examining the association between ideal instrumental support and HRQoL variables adjusted for age; SF-36: Medical Outcomes Study Short-Form 36; PC: physical component; MC: mental component; CI: confidence intervals**p<0.05; **p<0.01; ***<0.001*

Table 7 Associations between ideal informational support and HRQoL in APS

	Ideal Social Support – Informational (n= 270)				
SF-36 domains	***Information provided by GPs***	***Information provided on the internet***	***Information provided by support groups***	***Information provided on TV/leaflets***	***Information provided by consultants/charity***
PC	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)
Physical functioning	2.23 (-4.18, 8.64)	-0.64 (-6.27, 4.99)	4.18 (-1.39, 9.75)	3.20 (-2.37, 8.76)	-4.12 (-8.82, 0.59)
Role physical	-0.63 (-14.40, 13.15)	-1.76 (-13.84, 10.32)	6.04 (-5.94, 18.01)	11.41 (-0.48, 23.30)	1.37 (-8.80, 11.53)
Bodily pain	1.99 (-5.68, 9.66)	-1.46 (-8.25, 5.32)	2.19 (-4.55, 8.92)	5.00 (-1.69, 11.69)	-0.77 (-6.62, 5.07)
General health	0.42 (-4.87, 5.71)	1.75 (-2.91, 6.42)	2.68 (-1.95, 7.31)	1.01 (-3.63, 5.64)	-0.79 (-4.74, 3.16)
MC					
Vitality	3.34 (-1.97, 8.65)	4.24 (-0.44, 8.91)	5.85** (1.23, 10.46)	2.40 (-2.25, 7.06)	-1.33 (-5.30, 2.65)
Social functioning	2.29 (-5.24, 9.82)	0.20 (-6.46, 6.85)	3.18 (-3.43, 9.78)	1.69 (-4.91, 8.29)	-1.93 (-7.55, 3.70)
Role emotional	19.05** (5.39, 32.70)	-2.36 (-14.52, 9.81)	7.70 (-4.34, 19.75)	11.27 (-0.70, 23.25)	-2.34 (-12.55, 7.87)
Mental health	6.29** (1.35, 11.23)	3.49 (-0.91, 7.88)	3.81 (-0.55, 8.17)	2.19 (-2.18, 6.55)	-1.01 (-4.74, 2.72)

Multiple Linear Analysis examining the association between ideal informational support and HRQoL variables adjusted for age; SF-36: Medical Outcomes Study Short-Form 36; PC: physical component; MC: mental component; CI: confidence intervals **p<0.05; **p<0.01; ***<0.001*

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The relationship between social support and health-related quality of life in patients with antiphospholipid (Hughes) syndrome

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Objective. Antiphospholipid (Hughes) syndrome (APS) is recognised as a systemic autoimmune disease defined by recurrent thromboembolic events and/or pregnancy morbidity. Little is known about the psychological burden of this long-term condition. This study aims to explore the relationship between social support and health-related quality of life (HRQoL) in patients with APS.

Methods. 270 patients with a clinical diagnosis of APS participated in a cross-sectional online questionnaire survey. Data included: demographics, disease-related information, social support and HRQoL.

Results. Both perceived and ideal social support were associated with HRQoL in APS. Patients reported receiving insufficient social support. Perceived emotional support was related to physical functioning (B=7.77, p=0.006, 95% CI: 2.25, 13.29); perceived instrumental support was associated with bodily pain (B=17.52, p<0.001, 95% CI: 11.15, 23.90) and perceived informational support with physical and social functioning

(B=-6.30, *p*=0.05, 95% CI: -12.52, -0.08; B=8.06, *p*=0.02, 95% CI: 1.17, 14.94). Ideal emotional support was related to physical and social functioning (B=5.80, *p*=0.04, 95% CI: 0.26, 11.34; B=7.53, *p*=0.04, 95% CI: 0.55, 14.51); ideal instrumental support was associated with mental health (B=4.73, *p*=0.03, 95% CI: 0.38, 9.07) and ideal informational support with vitality (B=5.85, *p*=0.01, 95% CI: 1.23, 10.46).

Conclusion. Social support was linked to HRQoL in patients with APS. Insufficient social support was associated with limitations in various HRQoL domains. Increasing social support especially through provision of disease-specific education might contribute to improving HRQoL in patients with APS. Patient-tailored interventions addressing psychosocial aspects of living with APS are needed to improve patients' psychological and physical status.

Key words: Antiphospholipid (Hughes) syndrome (APS); social support; health-related quality of life (HRQoL); short-form health survey (SF-36)

Introduction

Antiphospholipid (Hughes) syndrome (APS) is recognized as a chronic autoimmune disease and is characterized by recurrent venous and arterial thrombosis, miscarriage, neurological features such as stroke, headache, fatigue, memory loss, and epilepsy [1, 2].

Approximately 20% of strokes in people under 40 years and up to 25% of all spontaneous miscarriages (two or more) or fetal losses are due to APS [2, 3]. APS affects predominantly women of childbearing age and is categorized as primary (PAPS) if there is no associated connective tissue disease and secondary (SAPS) if there is, mainly systemic lupus erythematosus (SLE), but also rheumatoid arthritis (RA), Sjogren's syndrome (SS), scleroderma, vasculitis, and Crohn's disease [4, 5, 6].

Chronic conditions such RA, SLE, ankylosing spondylitis (AS) and fibromyalgia syndrome (FS) have been shown to have a negative impact on health-related quality of life (HRQoL) especially if there is significant amount of pain involved [4, 5, 7, 8]. Similarly, in APS, HRQoL has been reported to be poorer compared to the general population [9, 10] especially in patients who had a history of arterial thrombosis [10].

The role of the social environment in patients' HRQoL is very important [11]. The term social support denotes the availability and provision of care and help from an individual's environment. There are several kinds of social support. Three types of social support often discussed in the literature are distinguished into tangible support such as instrumental support (e.g. assistance with medication/housework), informational support (e.g. education regarding the illness) and treatment strategies and recovery and

into intangible support in the form of emotional support (e.g. listening/sympathy) [12]. Social support can be problematic despite people's good intentions [13] when it involves excessive worry and unsolicited advice, denial of the existence of the illness and its impact on the patient's life, or support that is not consistent with patients' beliefs about their condition [13].

Social support is important in improving and maintaining both good physical and mental health in order to self-manage a chronic illness effectively [14, 15]. Support from others, computer-based support and educational interventions combined with self-management [16, 17] and internet support groups [18] have all shown beneficial effects. Elements included in support are also disease-related education such as diagnosis, treatment, and recovery. Increased levels of disease-specific knowledge were associated with stronger coping skills, perceptions and health behaviours, benefiting disease progression as well as psychological well-being [19, 20]. Social support can also play a mediating role through influencing self-esteem by increasing optimism and decreasing depression thus improving psychological adjustment to chronic illness [21]. Indeed, patients who received more emotional support on a daily basis reported better psychological status than those who did not [22].

Two levels of social support are described: perceived and ideal support. Perceived support refers to the support people perceive to be receiving from their environment while ideal support is the support they would still like to be receiving from friends and family based on their individual needs. It has been argued that the first is more important than the latter because the way patients interpret social support influences psychological adjustment and coping more than ideal support [23, 24]. In addition, lack

of understanding from their environment regarding their illness and its consequences contributes to poorer adjustment to chronic illness [23]. In the present study we explored both forms of social support because we attempted to evaluate the magnitude of discrepancy of perceived and ideal social support in patients with APS and whether this discrepancy was associated with their HRQoL. Furthermore, we wanted to assess how much social support patients with APS feel they still need compared to how much they feel they are receiving in order to be able to provide them with additional support to improve their HRQoL.

Availability of social support is related to improved health in patients with rheumatic diseases [25, 26]. Particularly, in SLE clinical variables appear to exert a minor influence on patients' HRQoL [5, 27] with psychosocial factors such as social support or helplessness having a significant impact [5, 28]. In addition, "invalidation" referring to lack of understanding or acknowledgment and rejection of the condition has been associated with poorer outcome in patients with rheumatic diseases such as FS and RA [29]. Findings from a literature review on the role of social support in SLE, indicated that social support contributes as a predictor of disease activity, damage and quality of life on both the physical and emotional level [30].

While social support has a beneficial impact on both HRQoL and adjustment to their illness in patients with rheumatic diseases, little is known about the role of social support in HRQoL in patients with APS. This highlights the need for the present study which aimed to explore the relationship between perceived and ideal social support and HRQoL in APS.

Methods

Participant selection and assessment

This was an internet-based cross-sectional survey. The survey was conducted through a link to an online questionnaire which was available at *KwikSurveys.com*. The link was included in an email that was sent to all members of the Hughes Syndrome Foundation (HSF) worldwide with a request to participate in the survey – if they fulfilled the eligibility criteria. The email was sent by the HSF manager to preserve confidentiality. Participants were given three weeks to complete the survey online after receipt of the email containing the link. As soon as a survey questionnaire was completed, a link leading to each participant's responses was automatically forwarded to the researchers' personal email inbox that was set up for the purpose of the study. The link expired 6 months after completion of the survey.

The survey consisted of three sections: (a) the SF-36 assessing health-related quality of life; (b) social support questions; and (c) demographic and disease-specific data. A reminder to complete the survey was sent four days before the expiry of the deadline. The HSF manager forwarded the link to 443 members worldwide to ensure anonymity of the participants. Inclusion criteria were that participants had to be over 18 years of age and have a clinical diagnosis of either PAPS or SAPS. The study received approval from the University of Nottingham Research Ethics Committee.

HRQoL measure

The SF-36 was employed in the current study due to its generic scope, as well as its reliability and validity in assessing HRQoL in healthy populations [31] and in other

diseases [32] despite not having been used in APS before. The SF-36 can also provide data on the influence of the disease on patients' physical psychological and social well-being [33, 34].

Specifically, the SF-36 measures eight domains relative to physical and psychological status which are termed "physical components" (PC) and "mental components" (MC). The physical components include: role physical (RP), general health (GH), bodily pain (BP), and physical functioning (PF) while the mental components encompass: role emotional (RE), vitality (VT), mental health (MH), and social functioning (SF). The self-administered standard version of the SF-36 was selected since it was based on self-completion. Multipoint scales (3 to 10 items) are used to score six of the eight domains while SF and BP are scored on a two-point scale (yes/no). Scale scores are computed by same scale item summation followed by transformation of raw scale score on a range from 0 (lowest possible level of functioning) to 100 (highest possible level of functioning) [36].

Demographics and disease-specific information

Demographics included questions on participants' age, gender and ethnic background. Information on type and time of diagnosis, co-morbidities, date of symptom onset, and number of medications prescribed was collected.

Social support survey

Social support was assessed on two levels, perceived and ideal, and on three subscales, emotional, instrumental and informational. The survey questions were presented in the

form of a set of multiple choice questions with 4 or 5 possible options *displaying various examples of social support scored on a two-point scale.* The participants had to indicate which of the available support options listed (e.g. *for **emotional support**: (a) listening; (b) understanding; (c) encouragement; (d) positive feedback; (e) willingness to learn more about the illness)* they felt they were receiving (perceived support) and which one(s) they would like to still be receiving (ideal support) by simply ticking the appropriate answer yes or no (please see Appendix 1).

Statistical Analysis

Participant characteristics summary measures and HRQoL scores were computed as means and standard deviations for continuous (approximate) normally distributed variables and frequencies and percentages for categorical variables. Normality of distribution of continuous summary scales (all *p*-values >0.05) was assessed with the Shapiro-Wilk test. Multiple linear regression analysis was performed to explore associations between social support and HRQoL in patients in APS and to examine whether perceived and ideal social support were associated with HRQoL. All analyses were adjusted for age. All *p*-values were two-sided throughout and significance level was set at 5% level. The data were analysed using SPSS version 21.

Results

Participant characteristics

The majority of participants were from the United Kingdom (61.9%). Approximately a quarter were from the United States (24.8%), and fewer from Australia (2.2%), Canada (1.9%) and several other countries. Response rate was 60%. 274 patients completed and returned the questionnaire survey out of a total of 443 individuals who were sent the questionnaire survey link. Four questionnaires were discarded due to insufficient data which resulted in 270 completed questionnaires being included in the analyses. Mean patient age was 45.2±12.1 (range: 18-86 years). The majority of the patients were female (84%; n=226) and 45% reported PAPS. Mean age for patients with PAPS was 42.6±11.6 years and for patients with SAPS 47.4±12.1 years. The mean time until receiving a clinical diagnosis for APS was 48.5±87.3 months for PAPS and 75.8±106.4 months for SAPS patients. PAPS patients were prescribed a mean of 3±2.8 medications while SAPS patients 7±5.2. SLE was reported by 43% (n=63) of SAPS participants. On average, participants completed the survey five years post-diagnosis.

Social support

Frequency statistics were computed separately for actual and idea social support measures. The majority of patients indicated that they were perceived to be receiving emotional support such as listening (78.7%), understanding (59%), encouragement (55.6%) but not positive feedback (34% vs 66%) and willingness on behalf of their family and friends to learn more about APS (44% vs 56%). In contrast, the majority of patients perceived not to be receiving instrumental support such as help with childcare and housework/shopping (85.1% and 51.9% respectively), provision of transportation (69.8%), financial help (73.5%) and someone to accompany them to GP and hospital

appointments (51.5%). Most of the information support, APS patients perceived to be receiving was derived from the internet (82.1%) and support groups (65.7%) whereas a minority of patients reported perceived informational support obtained from GPs (26.9%) and TV or leaflets (14.2%) (Table 1).

The main social support (ideal) that patients would like to receive were: understanding (67.9%), willingness to learn more about APS from family or friends (64.9%), information from GPs (74.3%), TV and leaflets (50%) (Table 1).

HRQoL

HRQoL scores were computed for all patients. Mean scores in six domains (RP, BP, GH, VT, SF and RE) were <60 which is the cut-off score reported to indicate highest specificity for functional limitations [51]. In the remaining two SF-36 domains (PF and MH), mean scores were >60. The mean HRQoL score was 64.4±20.6. Comparison between PAPS and SAPS patients showed poorer HRQoL scores for the PAPS group (< 60) in two domains (GH and VT) and better HRQoL scores (>60) in the remaining six domains (PF, RP, BP, RE, MH and SF) with a mean of 65.15±31.1. For SAPS patients, mean scores were <60 in seven of the SF-36 domains (RP, BP, GH, RE, VT, MH and SF) and >60 in one domain (PF) with a mean of 60.25±23.1.

Relationship between social support and HRQoL in APS

Perceived social support and HRQoL

Perceived social support was assessed on three levels: emotional, instrumental and informational. On the perceived emotional level, results showed that higher levels of encouragement were related to better physical functioning (B=7.77, p<0.01; 95%CI: 2.25, 13.29), better role physical functioning (B=15.83; p<0.01; 95%CI: 3.96, 27.70) and better general health (B=5.62; p<0.01; 95%CI: 1.02, 10.22) while less understanding from friends and family were associated with lower levels of vitality (B=-6.22, p<0.01; 95%CI:-10.91, -1.53). Lower provision of positive feedback was associated with poorer role emotional functioning (B=-13.88, p<0.05; 95%CI: -26.51, -1.25) and poorer mental health (B=-7.99, p<0.001; 95%CI: -12.52, -3.47) and similarly lower degree of willingness to learn more about APS was also related to poorer mental health (B=-4.27, p<0.05; 95%CI: -8.51, -0.02) (Table 2).

Results on perceived instrumental support indicated that lower provision of help with childcare was related to more limited social functioning (B=-9.21, p<0.05; 95%CI: -18.49, 0.07) whereas more support in terms of helping with housework and/or shopping were associated with better physical functioning (B=13.50, p<0.001; 95%CI: 8.17, 18.84), role physical (B=18.64, p<0.01; 95%CI: 6.88, 30.40), lower bodily pain (B=17.52, p<0.001; 95%CI: 11.15, 23.90), better general health (B=10.40, p<0.001; 95%CI: 5.94, 14.87), higher levels of vitality (B=8.85, p<0.001; 95%CI: 4.30, 13.39), and better social functioning (B=9.22, p<0.01; 95%CI: 2.71, 15.73). Provision of transportation was associated with better HRQoL in all domains except for mental health while financial help was associated with better physical functioning (B=7.93, p<0.01; 95%CI: 1.70, 14.16) and lower bodily pain (B=9.31, p<0.05; 95%CI: 1.77,

16.85). Attendance at General Practitioner (GP) and hospital appointments was also related to better HRQoL in the domains physical functioning (B=9.20, p<0.001; 95%CI: 3.71, 14.69), bodily pain (B=9.74, p<0.01; 95%CI: 3.09, 16.39), general health (B=5.53, p<0.05; 95%CI: 0.92, 10.14), and role emotional (B=12.14, p<0.05; 95%CI: 0.12, 24.15) (see Table 3).

Perceived informational support was associated with HRQoL in terms of information provided by GPs, support groups, and consultants/charity. Less information provided by GPs was associated with more limited physical functioning (B=-6.30, p<0.05; 95%CI: -12.52, -0.08), and poorer role physical performance (B=-19.37, p<0.01; 95%CI: -32.63, -6.11), more support provided by support groups was related to better social functioning (B=8.06, p<0.05; 95%CI: 1.17, 14.94) and less information from consultants/charity was related to poorer general health (B=-8.67, p<0.05; 95%CI: -16.72, -0.61) (Table 4).

Ideal social support and HRQoL

Ideal social support was also assessed on three levels: emotional, instrumental and informational. Patients reported the levels of social support they felt they still wanted to receive based on their needs. People who felt they still needed someone to listen to their concerns and worries would be more likely to have better physical functioning if they had this support (B=5.80, p<0.05; 95%CI: 0.26, 11.34) and higher levels of vitality (B=6.91, p<0.01; 95%CI: 2.32, 4.51). The need for understanding was linked to better HRQoL except for bodily pain and role emotional and the need for more frequent encouragement was associated with better physical functioning (B=7.78, p<0.01; 95%CI: 2.30, 13.26), role physical (B=14.46, p<0.05; 95%CI: 2.66, 26.26), and greater

vitality (B=5.16, p<0.05; 95%CI: 0.56, 9.77). Greater provision of positive feedback was associated with better role physical (B=16.35, p<0.01; 95%CI: 4.59, 28.12), greater vitality (B=5.29, p<0.05; 95%CI: 0.69, 9.90), and role emotional (B=13.13, p<0.05; 95%CI: 1.23, 25.04). Patients' greater need for their family and friends to learn more about APS was related to better role physical (B=15.99, p<0.01; 95%CI: 3.62, 28.36), and greater vitality (B=7.21, p<0.01; 95%CI: 2.42, 12.01) (Table 5).

Ideal instrumental support was associated with better HRQoL in all domains in terms of provision of help with housework and/or shopping and attendance at GP and hospital appointments (see Table 6). The need for provision of transportation was related to better HRQoL in all domains except role physical and role emotional (see Table 6).

There was an association between greater informational support provided by and better role emotional (B=19.05, p<0.01; 95%CI: 5.39, 32.70) and better mental health (B=6.29, p<0.01; 95%CI: 1.35, 11.23), while information from support groups was associated with greater vitality (B=5.85, p<0.01; 95%CI: 1.23, 10.46) (Table 7).

Discrepancy values between perceived and ideal social support

In order to examine discrepancy between actual and ideal social support in APS patients, the total values of each were computed for all three types of social support, i.e. emotional, instrumental and informational. Following that, a discrepancy value was obtained by subtracting the total actual support values from the total ideal support values for each of the three types of social support. The results indicated that the mean of the discrepancy value between actual and ideal emotional support (*M*=.064;

SD=2.42; N=268) as well as the mean of the discrepancy between actual and ideal instrumental support (*M*=-.011; *SD*=1.24; N=268) were relatively small. In contrast, the mean of the discrepancy between ideal and actual informational support (*M*=.23; *SD*=1.58; N=268) was large. Thus, it would seem that the informational support APS patients perceive to be receiving is far smaller than the support they ideally would need to be receiving. As far as informational and instrumental support was concerned, the ideal levels of social support did not appear to differ significantly from the perceived levels.

Discussion

This is the first study to examine associations between social support and HRQoL in patients with APS. HRQoL in individuals living with rheumatic and autoimmune diseases is affected to a significant extent [4, 5] with social support playing a significant role [18, 37-39]. However, very little research has been conducted into HRQoL and social support in patients with APS so far, to our knowledge. A variety of measures are available to assess HRQoL including generic and disease-specific instruments. Generic instruments can be employed across a range of different conditions while specific instruments are disease-adapted. APS-related symptoms vary significantly and can have an impact on patients' physical, social and emotional status [1].

Associations between perceived social support and HRQoL indicated that higher provision of instrumental support was related to better HRQoL in terms of patients' physical and mental status. Higher perceived emotional support, on the other hand, led to better mental health status probably because increased support in this domain may

contribute to patients getting more time to rest, socialize and experience less stress [43-46]. More perceived information provided by GPs was also related to better physical functioning and role physical, while information received from support groups was related to better social functioning and less information from consultants and the charity were related to poorer general health. This is in accordance with previous literature which suggests that doctor-patient communication plays a significant role in patients' health outcomes, quality of life, absence from work and treatment adherence [47]. It could be assumed that because of insufficient information provided, patients are not aware of the degree they should engage in various activities and this subsequently may have a negative effect on their physical health due to increased or decreased involvement.

Similarly, higher ideal social support was also linked to better HRQoL. People who felt they needed someone to listen to their concerns and worries were predicted to be more likely to have better physical functioning such as fewer limitations in performing physical activities, including bathing or dressing and experience greater vitality i.e. feeling more energetic. This could be attributed to the fact that people might be likely to receive some reassurance from their social circle that they are able to perform certain activities following the expression of their concerns or offer them additional support which might contribute to decrease the burden that affect their energy levels. This was also reflect in the fact that the need for more frequent encouragement was associated with better physical while greater provision of positive feedback was associated with better role physical greater vitality, and role emotional.

The need to feel understood by family and friends was linked to better HRQoL in all domains except for physical pain and role emotional. Indeed, negative social responses, particularly discounting (rejecting) and lack of understanding (not being acknowledged), were associated with poorer health among patients with fibromyalgia and rheumatoid arthritis [52]. Greater understanding would be derived from better knowledge of APS by the patient's family and social circle. Results showed that patients' greater need for their family and friends to learn more about APS was related to better role physical, and greater vitality. Ideal instrumental support was associated with better HRQoL in all domains in terms of provision of help with housework and/or shopping and attendance at GP and hospital appointments and greater informational support was associated with better role emotional and better mental health, while information from support groups was associated with greater vitality.

In order to assess whether the social support that patients reported to be receiving was significantly different to the support they felt they still needed, results did not show a statistically significant difference for emotional and instrumental support. However, there was a statistically significant difference between the informational support patients reported to be receiving and the informational support they felt they were still lacking highlighting the lack of awareness as well as health professional education and public awareness about APS. More knowledge of APS provided by health care professionals and the media might enhance patients' coping with the disease due to increased education on aspects such as self-management, and medication and more effective and helpful support from their families and friends.

There are some limitations to this study. First, the participants were members of the HSF which might have increased the likelihood of receiving higher social support compared to patients who do not belong to a charity. The data was based on self-report thus environmental or emotional influences could not be controlled. Diagnosis of APS could not be confirmed due to lack of access to patients' medical records or physical and laboratory examination. The survey was cross-sectional which prevents detection of change over time and assessment of causal relationships. Findings cannot be generalized due to the fact that the majority of patients were female and British. Ethnicity and culture has been suggested to affect perceived quality of life of individuals on dialysis after renal transplant with Asian renal patients perceiving HRQoL more negatively than white Europeans [47]. Factors such as major life events, for example death, divorce or severity of disease and depression status were not controlled for, any of which could potentially be related to poorer HRQoL in either group. Many factors such as bereavement, financial difficulties, depression and anxiety were also found to place a burden on HRQoL [11].

Strengths of this study, on the other hand, include a high response rate (60%), a satisfactory sample size providing sufficient power for analyses. The fact that a relatively non-researched patient population was assessed was a further advantage. Examination of all aspects of patients' well-being relating to the psychological, social and physical impact of APS and its influence by social support measures provided a more holistic approach and increased understanding of the degree and nature of the disease impact on patients' HRQoL.

Findings indicated that certain types of social support exert a significant influence on a variety of domains in APS patients' HRQoL. Patients reported receiving insufficient social support. By extension, this might be suggestive of the beneficial effect of social support on HRQoL in patients with APS either through medication adherence or also through more effective coping skills. Lack of support in terms of providing disease – and medication-specific information has been associated with decreased medication adherence in patients with autoimmune diseases [48]. In addition, increased informational support especially by knowledgeable health professionals might improve provision of support by patients' family and friends through reducing "invalidation" [29]. Particularly, due to the multi-faceted nature of APS, as is true of most autoimmune diseases, involving pain, disability, uncertainty about its progression and fear of treatment effects and based on the current findings it can be suggested that a combination of approaches and interventions could prove to be of great importance and help in improving adjustment and coping with APS. This combination would need to incorporate social approach and support from practitioners, family, friends, and co-workers, as well as elements from both the bio-psychosocial and biomedical frameworks [49, 50] tailored to the needs of APS patients. Specific strategies could be implemented through both primary and secondary care and include patient- and family/friends-education sessions delivered by specialist nurses. These sessions could provide disease- and treatment-specific information and self-management strategies such as International Normalised Ratio (INR) measuring, dietary advice and pacing to patients as well as disease-related information and ways of supporting their loved one in coping more effectively with APS to families/friends of patients with APS.

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Table 1 Computed values of results for ideal and actual social support

Actual Social Support - Emotional (n=268)	Yes	No	Ideal Social Support - Emotional (n=268)	Yes	No
Listening	211 (78.7%)	57 (21.3%)	Listening	136 (50.7%)	132 (49.3%)
Understanding	158 (59%)	110 (41%)	Understanding	182 (67.9%)	86 (32.1%)
Encouragement	149 (55.6%)	119 (44.4%)	Encouragement	127 (47.4%)	141 (52.6%)
Positive Feedback	91 (34%)	177 (66%)	Positive Feedback	125 (46.6%)	143 (53.4%)
Willingness to learn more about APS	118 (44%)	150 (56%)	Willingness to learn more about APS	174 (64.9%)	94 (35.1%)
Actual Social Support - Instrumental (n=268)			**Ideal Social Support - Instrumental (n=268)**		
Help with childcare	40 (14.9)	228 (85.1%)	Help with childcare	41 (15.3%)	227 (84.7%)
Help with housework/ shopping	129 (48.1%)	139 (51.9%)	Help with housework/ shopping	121 (45.1%)	147 (54.9%)
Provision of transportation	81 (30.2%)	187 (69.8%)	Provision of transportation	66 (24.6%)	202 (75.4%)
Financial help	71 (26.5%)	197 (73.5%)	Financial help	68 (25.4%)	200 (74.6%)
Attendance GPs/hospital appt	131 (48.9%)	137 (51.5%)	Attendance GPs/hospital appt	109 (40.7%)	159 (59.3%)
Actual Social Support - Informational (n=268)			**Ideal Social Support - Informational (n=268)**		
Information provided by GPs	72 (26.9%)	196 (73.1%)	Information provided by GPs	199 (74.3%)	69 (25.7%)
Information provided on the internet	220 (82.1%)	48 (17.9%)	Information provided on the internet	119 (44.4%)	149 (55.6%)
Information provided by support groups	176 (65.7%)	92 (34.3%)	Information provided by support groups	119 (44.4%)	149 (55.6%)
Information provided on TV/ leaflets	38 (14.2%)	229 (85.4%)	Information provided on TV/ leaflets	134 (50.0%)	134 (50.0%)
Information provided by consultants/charity (n=20)	19 (7.1%)	1 (0.4%)	Information provided by consultants/charity (n=42)	41 (15.2%)	1 (0.4%)

Table 2 Associations between perceived emotional support and HRQoL in APS

Perceived Social Support – Emotional (n= 270)					
SF-36 domains	***Listening***	***Understanding***	***Encouragement***	***Positive Feedback***	***Willingness to learn more about APS***
PC	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)
Physical functioning	-0.50 (-7.29, 6.30)	-2.62 (-8.31, 3.06)	7.77** (2.25, 13.29)	0.43 (-5.47, 6.33)	4.21 (-1.21, 9.62)
Role physical	5.90 (-8.68, 20.48)	-5.60 (-17.79, 6.60)	15.83** (3.96, 27.70)	4.84 (-7.82, 17.50)	0.32 (-11.37, 12.01)
Bodily pain	2.97 (-5.25, 11.19)	-2.23 (-9.08, 4.62)	6.62 (-0.08, 13.33)	0.43 (-6.68, 7.53)	1.35 (-5.21, 7.91)
General health	-2.74 (-8.40, 2.92)	-1.74 (-6.46, 2.98)	5.62** (1.02, 10.22)	-0.45 (-5.35, 4.46)	0.57 (-3.96, 5.10)
MC					
Vitality	-3.66 (-9.35, 2.03)	-6.22** (-10.91, -1.53)	1.74 (-2.94, 6.41)	-4.23 (-9.13, 0.68)	-3.62 (-8.15, 0.92)
Social functioning	-3.82 (-11.88, 4.25)	-4.60 (-11.30, 2.11)	1.82 (-4.80, 8.43)	-3.64 (-10.61, 3.33)	-3.03 (-9.47, 3.41)
Role emotional	-9.60 (-24.24, 5.03)	-7.56 (-19.83, 4.71)	-2.45 (-14.55, 9.65)	-13.88* (-26.51, -1.25)	-10.38 (-22.06, 1.31)
Mental health	-3.44 (-8.78, 1.90)	-3.99 (-8.43, 0.44)	-2.57 (-6.95, 1.81)	-7.99*** (-12.52, -3.47)	-4.27* (-8.51, -0.02)

Multiple Linear Analysis examining the association between perceived emotional support and HRQoL variables adjusted for age; SF-36: Medical Outcomes Study Short-Form 36; PC: physical component; MC: mental component; CI: confidence intervals **p<0.05; **p<0.01; ***<0.001*

Table 3 Associations between perceived instrumental support and HRQoL in APS

	Perceived Social Support – Instrumental (n= 270)				
SF-36 domains	***Help with childcare***	***Help with housework/ shopping***	***Provision of transportation***	***Financial help***	***Attendance at GPs/ hospital appointments***
PC	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)
Physical functioning	0.24 (-7.63, 8.10)	13.50*** (8.17, 18.84)	15.03*** (9.26, 20.81)	7.93** (1.70, 14.16)	9.20*** (3.71, 14.69)
Role physical	1.09 (-15.83, 17.99)	18.64** (6.88, 30.40)	20.20** (7.40, 32.99)	11.21 (-2.28, 26.69)	8.92 (-3.06, 20.91)
Bodily pain	0.15 (-9.50, 9.81)	17.52*** (11.15, 23.90)	14.59*** (7.51, 21.67)	9.31* (1.77, 16.85)	9.74** (3.09, 16.39)
General health	0.75 (-5.82, 7.31)	10.40*** (5.94, 14.87)	6.03* (1.03, 11.03)	3.88 (-1.36, 9.12)	5.53* (0.92, 10.14)
MC					
Vitality	-0.08 (-6.69, 6.52)	8.85*** (4.30, 13.39)	8.48*** (3.50, 13.46)	1.67 (-3.62, 6.95)	1.18 (-3.50, 5.87)
Social functioning	-9.21* (-18.49, 0.07)	9.22** (2.71, 15.73)	10.43** (3.34, 17.52)	2.10 (-5.39, 9.58)	5.26 (-1.34, 11.86)
Role emotional	-8.29 (-25.25, 8.67)	5.59 (-6.45, 17.62)	14.95* (1.97, 27.92)	7.15 (-6.44, 20.74)	12.14* (0.12, 24.15)
Mental health	-3.26 (-9.44, 2.93)	2.46 (-1.91, 6.83)	3.63 (-1.12, 8.38)	0.33 (-4.63, 5.30)	-0.22 (-4.62, 4.18)

Multiple Linear Analysis examining the association between perceived instrumental support and HRQoL variables adjusted for age; SF-36: Medical Outcomes Study Short-Form 36; PC: physical component; MC: mental component; CI: confidence intervals **p<0.05; **p<0.01; ***<0.001*

Table 4 Associations between perceived informational support and HRQoL in APS

	Perceived Social Support – Informational (n= 270)				
SF-36 domains	***Information provided by GPs***	***Information provided on the internet***	***Information provided by support groups***	***Information provided on TV/leaflets***	***Information provided by consultants/charity***
PC	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)
Physical functioning	-6.30* (-12.52, -0.08)	-2.17 (-9.50, 5.16)	4.20 (-1.65, 10.05)	4.42 (-3.49, 12.33)	-3.02 (-12.74, 6.69)
Role physical	-19.37** (-32.63, -6.11)	-3.52 (-19.16, 12.11)	6.93 (-5.65, 19.51)	8.03 (-8.99, 25.05)	-14.63 (-35.45, 6.20)
Bodily pain	-6.12 (-13.63, 1.39)	3.02 (-5.65, 11.69)	4.57 (-2.50, 11.64)	6.15 (-3.37, 15.66)	-5.52 (-17.19, 6.15)
General health	-0.50 (-5.71, 4.70)	0.41 (-5.61, 6.43)	2.07 (-2.80, 6.95)	2.89 (-3.66, 9.44)	-8.67* (-16.72, -0.61)
MC					
Vitality	-4.59 (-9.80, 0.62)	1.50 (-4.56, 7.56)	0.65 (-4.26, 5.56)	-2.40 (-8.99, 4.19)	-1.18 (-9.35, 6.99)
Social functioning	-6.79 (-14.16, 0.58)	-2.63 (-11.20, 5.94)	8.06* (1.17, 14.94)	8.86 (-0.42, 18.14)	-9.34 (-20.85, 2.18)
Role emotional	-11.02 (-24.49, 2.40)	-13.45 (-29.21, 2.31)	5.10 (-7.57, 17.76)	-2.99 (-20.12, 14.13)	-8.62 (-29.59, 12.36)
Mental health	-1.12 (-6.03, 3.80)	-4.08 (-9.74, 1.59)	-1.09 (-5.69, 3.52)	-1.71 (-7.90, 4.48)	-3.72 (-11.38, 3.94)

Multiple Linear Analysis examining the association between perceived informational support and HRQoL variables adjusted for age; SF-36: Medical Outcomes Study Short-Form 36; PC: physical component; MC: mental component; CI: confidence intervals**p<0.05; **p<0.01; ***<0.001*

Table 5 Associations between ideal emotional support and HRQoL in APS

	Ideal Social Support – Emotional (n= 270)				
SF-36 domains	***Listening***	***Understanding***	***Encouragement***	***Positive Feedback***	***Willingness to learn more about APS***
PC	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)
Physical functioning	5.80* (0.26, 11.34)	6.21* (0.31, 12.10)	7.78** (2.30, 13.26)	3.99 (-1.54, 9.54)	4.91 (-0.89, 10.71)
Role physical	5.76 (-6.21, 17.73)	14.27* (1.61, 26.93)	14.46* (2.66, 26.26)	16.35** (4.59, 28.12)	15.99** (3.62, 28.36)
Bodily pain	0.23 (-6.50, 6.96)	5.87 (-1.26, 12.99)	2.66 (-4.04, 9.35)	-0.005 (-6.70, 6.69)	0.75 (-6.27, 7.76)
General health	2.06 (-2.57, 6.70)	5.66* (0.77, 10.56)	3.64 (-0.96, 8.24)	1.41 (-3.21, 6.02)	2.30 (-2.53, 7.14)
MC					
Vitality	6.91** (2.32, 4.51)	9.48*** (4.64, 14.32)	5.16* (0.56, 9.77)	5.29* (0.69, 9.90)	7.21** (2.42, 12.01)
Social functioning	5.55 (-1.03, 12.12)	7.53* (0.55, 14.51)	6.31 (-0.23, 12.85)	4.10 (-2.47, 10.66)	4.77 (-2.10, 11.65)
Role emotional	9.91 (-2.10, 21.92)	4.88 (-7.95, 17.72)	7.69 (-4.29, 19.67)	13.13* (1.23, 25.04)	8.41 (-4.15, 20.96)
Mental health	2.32 (-2.06, 6.69)	6.17** (1.57, 10.78)	2.55 (-1.81, 6.90)	1.68 (-2.68, 6.04)	1.74 (-2.83, 6.30)

Multiple Linear Analysis examining the association between ideal emotional support and HRQoL variables adjusted for age; SF-36: Medical Outcomes Study Short-Form 36; PC: physical component; MC: mental component; CI: confidence intervals **p<0.05; **p<0.01; ***<0.001*

Table 6 Associations between ideal instrumental support and HRQoL in APS

	Ideal Social Support – Instrumental (n= 270)				
SF-36 domains	***Help with childcare***	***Help with housework/ shopping***	***Provision of transportation***	***Financial help***	***Attendance at GPs/ hospital appointments***
PC	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)
Physical functioning	-0.64 (-8.56, 7.28)	10.77*** (5.33, 16.20)	11.28*** (4.99, 17.58)	3.67 (-2.72, 10.07)	11.81*** (6.29, 17.33)
Role physical	-1.50 (-18.54, 15.54)	20.03*** (8.29, 31.77)	12.93 (-0.83, 26.69)	11.59 (-2.05, 25.24)	18.78** (6.77, 30.79)
Bodily pain	-4.52 (-14.13, 5.09)	12.01*** (5.45, 18.58)	10.63** (2.95, 18.31)	4.50 (-3.16, 12.17)	9.87** (3.12, 16.62)
General health	0.75 (-5.82, 7.31)	8.48*** (3.95, 13.00)	5.58* (0.25, 10.91)	2.41 (-2.91, 7.73)	7.36** (2.71, 12.01)
MC					
Vitality	3.91 (-2.68, 10.50)	11.69*** (7.24, 16.14)	9.35*** (4.07, 14.64)	5.17 (-0.15, 10.49)	9.86*** (5.25, 14.47)
Social functioning	0.83 (-8.52, 10.18)	11.82*** (5.37, 18.28)	11.88*** (4.37, 19.40)	1.64 (-5.94, 9.22)	9.94** (3.31, 16.58)
Role emotional	0.97 (-16.15, 18.08)	16.75** (4.85, 28.66)	12.12 (-1.72, 25.96)	10.53 (-3.26, 24.32)	14.28* (2.07, 26.48)
Mental health	0.83 (-5.37, 7.03)	4.73* (0.38, 9.07)	5.79* (0.77, 10.82)	3.56 (-1.45, 8.57)	4.46* (0.02, 8.90)

Multiple Linear Analysis examining the association between ideal instrumental support and HRQoL variables adjusted for age; SF-36: Medical Outcomes Study Short-Form 36; PC: physical component; MC: mental component; CI: confidence intervals**p<0.05; **p<0.01; ***<0.001*

Table 7 Associations between ideal informational support and HRQoL in APS

	Ideal Social Support – Informational (n= 270)				
SF-36 domains	***Information provided by GPs***	***Information provided on the internet***	***Information provided by support groups***	***Information provided on TV/leaflets***	***Information provided by consultants/charity***
PC	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)
Physical functioning	2.23 (-4.18, 8.64)	-0.64 (-6.27, 4.99)	4.18 (-1.39, 9.75)	3.20 (-2.37, 8.76)	-4.12 (-8.82, 0.59)
Role physical	-0.63 (-14.40, 13.15)	-1.76 (-13.84, 10.32)	6.04 (-5.94, 18.01)	11.41 (-0.48, 23.30)	1.37 (-8.80, 11.53)
Bodily pain	1.99 (-5.68, 9.66)	-1.46 (-8.25, 5.32)	2.19 (-4.55, 8.92)	5.00 (-1.69, 11.69)	-0.77 (-6.62, 5.07)
General health	0.42 (-4.87, 5.71)	1.75 (-2.91, 6.42)	2.68 (-1.95, 7.31)	1.01 (-3.63, 5.64)	-0.79 (-4.74, 3.16)
MC					
Vitality	3.34 (-1.97, 8.65)	4.24 (-0.44, 8.91)	5.85** (1.23, 10.46)	2.40 (-2.25, 7.06)	-1.33 (-5.30, 2.65)
Social functioning	2.29 (-5.24, 9.82)	0.20 (-6.46, 6.85)	3.18 (-3.43, 9.78)	1.69 (-4.91, 8.29)	-1.93 (-7.55, 3.70)
Role emotional	19.05** (5.39, 32.70)	-2.36 (-14.52, 9.81)	7.70 (-4.34, 19.75)	11.27 (-0.70, 23.25)	-2.34 (-12.55, 7.87)
Mental health	6.29** (1.35, 11.23)	3.49 (-0.91, 7.88)	3.81 (-0.55, 8.17)	2.19 (-2.18, 6.55)	-1.01 (-4.74, 2.72)

Multiple Linear Analysis examining the association between ideal informational support and HRQoL variables adjusted for age; SF-36: Medical Outcomes Study Short-Form 36; PC: physical component; MC: mental component; CI: confidence intervals **p<0.05; **p<0.01; ***<0.001*